

## CHAPTERS

### CONCLUSIONS

#### Summary of the Research Process

We presented the findings reported in Chapter 3 in the format used for the previous *Jackson* Longitudinal Study Reports. They are based on six interview and observation visits starting with T<sub>0</sub> data (gathered from a representative sample of 60 individuals who were living at either Los Lunas or Ft. Staruon hospital) and ending with T<sub>5</sub> data (gathered from 36 individuals living in community-based residences). As in the earlier *Jackson* reports we presented our findings in a comparative fashion. We interviewed and observed up to 96 residents each year as they gained experience living in the community and compared the data at each point with the other points and to the pre-move *baseline* data. In addition, where possible for this final report, we also compared mean (or average) responses in *aggregated* post-move data (T1 through T<sub>5</sub>) to the mean response of the pre-move sample, to assess the statistical significance of the pre- and post-move mean difference. (See the discussion on page 24.)

*In the final report we try to reach some general conclusions by identifying **broad** patterns in the data.*

In this chapter, we will first summarize the conclusions drawn from our findings in Chapter 3. Some are illustrated by reference to the case studies presented in Chapter 4. Rather than focusing on trends for single indicators, we look more broadly at multiple indicators and patterns that emerge from the data, and raise issues and questions (even if we cannot answer them) about why these patterns may exist.

In a "special analyses" appendix, (**Appendix E**) we examine more complex relationships. First, we explore in more depth a series of interview items regarding the frequency of residents' participation in recreational activities. The apparent decline in recreational opportunities had been an issue of concern to the DDPC and to parents since it was identified in the JLS Year 1 Report and in our first year Family Survey.

Finally, we observe the relationship between an individual's "ICAP Level" (see the explanation on page 17 in Chapter 3) and measures of opportunity and choice. This is updated from the Year 4 report.

The "special analyses" illustrate additional work that might be undertaken using this data set or after gathering additional data, to further explicate the personal and environmental factors that may hinder or facilitate the success of individuals with developmental disabilities in transition from institutional to community living arrangements.

## Major Trends Observed in the Time-Series Data

*We revisited Year 3's "rising expectations" hypothesis as we analyzed and synthesized our findings.*

In the Year 3 report, we hypothesized a "quiet revolution of rising expectations" to explain some contradictions that were appearing in our data. We noticed that as residents were becoming increasingly empowered in the community setting, some were also expressing increased dissatisfaction with some aspects of their lives. We wondered, in short, whether **as residents in the community gained opportunities to make choices in some areas of their lives, they were more likely to express dissatisfaction about those areas in which they didn't have such choices.** Although this hypothesis was *not* strongly supported by the Year 4 data, we were reluctant to discard it, as we began to interpret the major trends in our data for this final report.

The bulleted paragraphs below summarize our overall conclusions. (Page numbers refer generally to the findings supporting these conclusions.)

*(Pages 25-27)*

More *Jackson* Class members like living in the community-based residential environments more than liked living in the institutional settings. This trend is supported over time, and is very stable. Their reasons vary over time, but the availability of social opportunities has become the aspect of "living here" they most like.

*(Pages 28-29)*

More individuals would prefer to stay at their current residence rather than to move, when posed with the alternatives. (This was true at every point except T3, in marked contrast to the 75% of the T<sub>0</sub> sample that said they'd rather move.) Of those who would rather move, most cited wanting to be with their family. For some this is a practical impossibility. Many realized this and said that the ability of their family to provide needed care would make such a move difficult. Expressing such a preference *did not* mean residents were dissatisfied with their current home. We regard this is an important measurement of consumer satisfaction.

*(Pages 30-33)*

Our field research associates have observed, over time, the absence of barriers to residents' mobility, in addition to improved quality of the physical environment in the community homes. These observations seem important as proxy measures of residents' Quality-of-Life.

*(Pages 33-34)*

Physical access to the community for Jackson class members has improved dramatically. Between 73% and 88% of all post-move observations indicate excellent or acceptable access to the community. This observation parallels our finding that more individuals either have the adaptive equipment they need or have less need for such equipment in the community environment. The case of "Rosa" may be typical of the synergistic effects of improvements in community access and personal functioning that can occur in community-based environments. Additional research could verify or falsify this connection.

(Pages 36-37)

In the institutions and even more so in the community homes the vast majority of residential staff observed were found to speak and act respectfully in their relationships with *Jackson* Class members ( Danny s case however demonstrates that instances of staff insensitivity could not always be apparent to our researchers ) Additionally most staff members across living environments are at least acceptably knowledgeable about the health needs of their *Jackson* clients However the level of staff knowledge is decreasing slightly over time in the community We view this to be largely a function of rapid turnover among residential staff (Our research associates have reported that weekend staff members in some situations have often not known much about the health status of the residents)

(Pages 37-38)

Additional evidence of greater respect for the individual in the community can be seen in better provision of private space and property and in staffs encouragement of behavior to enhance clients personal well being There is however a tension between this goal and that of offering the client as much choice as possible In the case of Ben it is possible that too much choice given soon after his move to the community led to difficulties that were only overcome when he moved into a new living situation where greater structure as well as more personal care were provided

(Pages 42-44)

The leisure activities *Jackson* Class members can participate in tend to be driven by availability For instance participation in swimming was far greater in the institution because there was a swimming pool on campus In the community residences individuals enjoy more freedom to select a variety of activities that are facilitated or hindered by their proximity agency resources the sensitivity of staff to the preferences of the clients and their ability to satisfy them For instance Dixie s desire for long drives in the country cannot always be accommodated because of resource constraints but staffs respect for her desire to be a homebody also reduces her level of recreational activity (For more on this issue see the Special Analyses appendix)

(Pages 45-48)

More members of the *Jackson* Class tend to be making friends *both* inside and outside their residences For a majority a process of integration of *Jackson* class members into the community is occurring This trend is also supported by the observation that residents are less and less dependent upon staff for their friendships (This is illustrated by the increase in the percentage of special friends who are peers ) Other indicators substantiate increasing integration into the community For instance *more Jackson Class members living in community based residences are visiting their families more* often than they did in the residential setting

(Pages 51-56)

- By a number of measures, more *Jackson Class* members in the community than in the institutions are enjoying greater freedom of choice. This can be seen most dramatically in the difference in responses to the question, "Can you decide not to do some things if you do not want to?" Other indicators supporting the proposition that *Jackson Class* members' freedoms have increased include being alone "when you want to," selecting clothes, buying clothes *with help*, and more opportunities to "buy what you want." Though the statistical significance of some of the findings is not strong, on almost every indicator of choice, there is a positive, upward trend in observations of acceptable opportunities. Moreover, the JLS field research associates' observations reported strong gains in individuals' opportunities to make choices.

(Pages 58-59, 41)

- In one domain, however, that of the *Jackson Class* community residents' choice of day programs, ("school, training or work") their choices are just as limited as in the institutions. For most, "someone else" picked their program. Moreover, this finding accompanies evidence of declining satisfaction ("Do you like it?") among participants in day programs. Only a minority of residents expresses dissatisfaction, but it appears to be a growing minority

Most of our case studies illustrate the importance of "work" to the *Jackson Class* members' satisfaction with their lives. "Dixie" has not been happy at work since leaving Los Lunas. "Andy," "Ben" and "Jeff" (all relatively high functioning individuals) derive much of their self-esteem and satisfaction from their jobs, which all were involved in choosing. (In this respect, the individuals selected for our case studies were atypical of the samples.) Only "Rosa" and "Danny" lacked day programs, because of staff decisions about their ability to succeed in them (one for physical, and one for emotional, reasons).

The question of "work" or day programs remains the most significant anomaly in the general pattern of improvement in the *Jackson* clients' satisfaction with their lives in the community. It is the single area in which it appears our "rising expectations" hypothesis is still supported by the data after five years. We deal with one aspect of this issue - "Who chooses?" - in the Special Analyses appendix.